How medical services mask provision of non-medical supportive care in palliative oncology ?

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ABSTRACT

OBJECTIVES

In the context of cancer, non-medical supportive care improves quality of life. While policymakers expect it to be cheaper than high-tech medical care, we hypothesized that it is in fact embedded in and camouflaged by hospital medical services.

METHODS

In a cross-sectional descriptive study, we conducted qualitative interviews with healthcare providers, patients and family caregivers in France. We first performed a functional analysis to identify non-medical supportive care functions provided or received and then developed a one day cohort study of patient in hospital or hospital at home to determine which non-medical care functions were provided and in what priority.

RESULTS

79 healthcare providers, patients and family caregivers were interviewed and 109 patient files were analysed in the cohort study. Providers declared they were highly solicited for non-medical reasons like moral, emotional support, or respite, that we listed and grouped into 5 categories: physical, moral, or financial support, coordination of care and dealing with legal and technical constraints. The cohort study determined that 30 patients (27%) were hospitalised for non-medical reasons. A diversity of services were provided: physical support (n=4), moral support (n=13), financial support (n=1), coordination of care dysfunction (n=12), legal constraint (n=1).

CONCLUSION

Medical care is not sufficient for the support of advanced cancer patients. Even though equivalence of care is guaranteed at home, non-medical services are provided within hospital because they are not provided or funded anywhere else. Non-medical care performs a variety of social, financial, psychological and legal functions needed by patients and family caregivers.

Keywords : supportive care, healthcare system barriers, patient relation, family caregivers, oncology healthcare providers

INTRODUCTION

Supportive care is today essential in the prevention and management of the adverse effects of cancer and treatments: pain reduction, control of symptoms and side effects to alleviation of social and emotional burdens.

While the medical aspects of supportive care such as pain and symptom management are increasingly documented in the literature, others are still neglected, such as psychological or moral support [1] and sacrificed in complex, fragmented and bureaucratic healthcare systems. Navigating in these systems remains a well-known obstacle to continuity [2–5] and to access to care itself [6].

Supportive care is appropriate at any stage of cancer management [7], however, most is focused on end-of-life, early euphemism for palliative care. It gave healthcare providers a term that did not imply that recovery was unlikely, as they were not at ease with discussing death [8] or because they believed that such discussions were detrimental to hope, an important element of patient management [9,10].

How non-medical supportive care is integrated into healthcare systems is mainly documented with studies of coordination of care among medical specialties [4]. The need for personal attention and communication is mainly referring to the lack of attention by doctors [11], or package in depression treatment by psychosocial intervention [12]. Their provision in the context of hospital services has scarcely been analysed.

The French medical system is dominated by a large use of hospital facilities. Because the medical treatment of cancer requires a high level of expensive technical and professional support, there is a pressure on hospitals to restrict their care to strictly medical functions, whether these are curative or supportive, and to locate palliative and non-medical supportive care services outside hospital, especially at home. But financial support is easier to find when hospital provides or help to provide it.

Despite an extramural medical supportive care services that tried to develop on offer, and the theoretical assumption that patients should be at hospital for medical reasons only, we hypothesized that patients often come to hospital for non-medical supportive care, and often receive what they come for. The implications of this choice are significant for healthcare costs (home vs. hospital) and for organisation of care. This led us to ask to what extent are non-medical supportive care services for patients with advanced cancer requested and provided in hospitals and masked as medical services? We thus aimed to explore the experiences of end-of-life cancer patients, family caregivers and healthcare professionals of requesting/receiving and providing non-medical supportive care in French oncology hospitals and their associated structures. We aimed to identify and categorize non-medical functions sought and provided, and determine which non-medical functions were provided to patients.

METHODS

Study design and timeline

The qualitative study was based on data collected from 2012 to 2013 in the DOveHO program, analysing cancer patients' preferences for supportive care at home versus at hospital and their reasons for those preferences, how the organisation of care in oncology might influence these preferences, and the costs associated with each option [13].

It consisted of three phases: 1) a cross-sectional descriptive study of cancer patients, their families and healthcare providers in the Rhone-Alpes Region regarding their experience of giving and receiving care; 2) a functional analysis of non-medical supportive care requested and provided; 3) a one day cohort study of advanced cancer patients hospitalised at home, in a supportive care unit located in a cancer institute and in a palliative care unit in a follow-up and rehabilitative care hospital located in the same geographic area.

Functional analysis is often used by industries to define the purposes of the goods or services they market [14][15]. This analyse accounts for both material and non-material outcomes of products and services. This approach is

particularly pertinent in healthcare organisations, which mainly analyse their services in terms of survival or functional quality of life [16].

Setting

We studied two hospitals and their associated services in the Rhône-Alps region. The patient population they serve is heterogeneous both socio-demographically and in terms of cancer pathologies. Both, Lucien Neuwirth Cancer Institute (private non-profit) and Michalon hospital (public) have similar organisational structures. Each has a complex network of associated but independent units including hospital at home, palliative care unit in local hospital, and other rehabilitation services.

The design was based on consolidated ground of research that emerged from previous studies [17,18] based on grounded theory principles[19].

The study obtained ethics approval by the Ethics Committee of the Comprehensive Cancer Centre Léon Bérard that supervised the project. Participants gave informed consent before taking part.

Participants and recruitment

Cross-sectional descriptive study: Purposive sampling was performed to catch a maximal variation of patterns with various categories of healthcare providers and support workers as well as with patients, caregivers and patient associations that would enable us to triangulate information collected [20]. Hospital doctors and patient associations were asked to suggest patients and caregivers for recruitment.

No particular stage or kind of cancer was targeted, as the goal was to explore non-medical supportive care in the broadest sense. Potential participants were presented with a description of the study and asked to call to make an appointment for an interview or leave their phone number. We did not attempt to recruit an equal number of participants from each site as site comparison was not an objective of this study. We stopped data collection when saturation point was achieved.

When we presented the functional analysis (step 2) to staff at Lucien Neuwirth Cancer Institute and associated services they proposed to perform a cohort study. On a given day we evaluated the extent of the non-medical care that they provided. In a context in which the medical culture of cure predominates and non-medical support is undervalued, these health professionals were motivated by a sense that the extent of non-medical support care they offer is more significant than the healthcare organisation decision makers realize. Three doctors, heads of department, examined active patient files to look for functions provided other than the medical one. Informed consent was not required because only doctors analysed the situation and didn't give any identifying information about patient. Criteria for inclusion of patient files was the situation where medical assistance was not determinant in their presence in the service considered. Patient from hospital or palliative care unit could have been at home with hospital at home, and patient in hospital at home could have been technically at home with a lighter assistance.

Data collection procedures

We developed three separate interview guides for individual semi-structured interviews with healthcare professionals, patients/ family caregivers/associations. Healthcare professionals were asked about their practices and the kind of care provided. Patients and their families were asked to talk about their care, what had helped them or been problematic, the kinds of services they had received and their preferences about location of care. Patient associations were asked about their opinion of the organisation of care. The interviews were conducted by researchers and were around 45 minutes each.

We then performed a functional analysis, coding the entire corpus by identifying expressions of need and the responses of the healthcare system, and then classified them according to their function. Functions were grouped into three categories of the functional analysis methodology [14] :

(1) Service functions, i.e. what is directly delivered to patients and identified by them as a response to their need (i.e. receiving care)? Services functions were sub-classified for each patient into primary and secondary functions. Primary functions described the main purpose of the service delivered (for example, chemotherapy). Secondary functions were linked to and justified by the primary functions (for example, social assistance for financial problem).

(2) Technical functions, i.e. what is necessary to produce the service functions, but will not necessarily be visible to the patient except when the system dysfunctions (for example, lack of interprofessional coordination) ?

(3) Constraint functions, i.e. those imposed by the technical or legal context (for example, medico-legal rules about safety precautions).

The 29th of October 2013 at the hospitalwe conducted the cohort study: information on place (rural/urban), sex, state of health, family situation, presence of caregivers, cancer treatment ongoing, and description of functions performed (physical, moral or financial relief, managing constraints) was gathered.

RESULTS

Cross-sectional qualitative study

Eighty-one potentially eligible participants were solicited. Two declined to participate (one cancer network refused as it was under restructuring, one psychiatrist did not get the message in time). Forty-eight were healthcare professionals.

We held face-to-face interviews with 79 persons: 27 physicians (hospital GPs, external GPs, internists, oncologists, palliative care physicians), 16 nurses, 6 personal carers (providing goods and services to patients), 5 social workers, 2 psychologists, 2 aestheticians, 6 members of patient associations (end-of-life support, breast cancer, colostomy, cancer league), 12 patients (nine women and three men with cancer of any type and at any stage, working or retired), 2 family caregivers of patients undergoing treatment and 3 caregivers of people who had since died.

Functional analysis was performed on data from the cross-sectional qualitative (see Table 1). Usually, these functions appear in the transcripts in the form of verb describing the action sought, and a noun that acts as a measure of the intensity or effect of the action. In our case, we tried to name as precisely as possible every kind of support described in the interviews that was not strictly medical, and associated it with more generic terms like “protecting patient from familial conflicts”. The generic terms was grouped in five sections.

Table 1

Functionalities by sections

Procuring physical relief	Prolong life span
	Reduce physical pain
	Preserve or recall physical functions
	Slow down physical deterioration
	Assure daily living requirements : housing, hygiene, meals
Procuring mental relief	Reassure ill person and families (safety, availability, continuity)
	Reassure about possibility of appeal if anything wrong
	Facilitate social relationship with other ill persons
	Protect family relationships
	Protect help natural caregivers face consequences of illness
	protect family from being overwhelmed by illness (in particular children)
	Protect from contact with other ill persons
	Protect from family conflict
	Protect stable family relationships
	Protect ill person's privacy
	Protect ill person's identity
	Protect ill person's social network
	Protect ill person's autonomy
	Help ill person set life goals
	Accompany ill person and families when illness is announced
	Accompany ill person and families when worsening of illness is announced
	Accompany ill person and families when they are physically deteriorating
	Accompany ill person and families when they are facing the threat of approaching death
	Accompany ill person and families when they are dying
Meeting the costs generated by pathology	Meeting costs of care
	Meeting costs of accompanying ill person through additional benefits
	Meeting costs of accompanying ill person through access to residential facilities
	Meeting costs of accompanying ill person through access to services on prescription
	Meeting costs of accompanying ill person through other assistance to the ill person and their family
	Guaranteed income
Coordinating care givers and arbitrating constraints	Insure team stability
	Help ill person and family with health system complexity
	Help meeting appropriate resources
	Coordinate medical skills (emergency procedures, pain management…)
	Coordinate caregivers
	Coordinate logistics and social skills
	Adapt to diversity of ill person (languages, specific needs…)
	Face with objectives and constraints of workers and institutions
	Face with divergent objectives
	Insure solvency of institutions and caregivers
Respecting constraints	Respect legal and technical obligation
	Respect law and rules

	Respect technical constraints

(1) Procuring physical relief

The first section is in keeping with the main mission of healthcare : prolong life, reduce physical pain, and preserve capacity, but also includes the management of housing, food and hygiene among isolated patients. . French hospitals have traditionally played this social role of last resort.

All participants consider that patient need medical or nursing consultations while under treatment, as the side effects or the cancer itself continues to cause physical deterioration, and generally consider them well served on that point.

(2) Procuring mental relief

The second falls under non-medical palliative care services, particularly the provision of moral support. This could be a need for attention or social support, or a patient's concern about her family caregiver needing respite. These functions make up a large part of professionals' practice, yet they are often not considered a priority in high-tech care contexts.

Medical and nursing cares were the patient's only need if they had family caregivers who were helping them face the financial and psychological burdens. It doesn't mean that they do not need attention from professional caregivers, but discussions they have during medical assistance are sufficient to help them, or not but they do without.

When patients presents psychological problems, healthcare provider may refer them to a psychologist. Some patients in need of moral support do agree to be referred to another professional such as a psychologist, a social worker or a priest for example. In this case supportive care consists of finding the appropriate person, but often the assistance that patient and family are seeking is more personal attention from their own attending physician. Patients expressed non-medical needs directly to diverse healthcare providers when they feel at ease to talk, or indirectly when they do not, and frequently use pain to gain the attention they need. In addition to its greater legitimacy in the healthcare system, the request for medical care is easier to express than distress.

Among family caregivers, not knowing how to cope is often experienced as a failure in their role as caregiver. It is easier to mention physical deterioration and pain than difficulty in coping. Attention and help given to family caregivers is as important as help given to patients. They need help to cope with their own distress, and to continue to help their loved ones for as long as they can, possibly until they die. They also play a crucial role in the organization of care. Helping family caregivers allows more patients to stay longer at home instead of being hospitalized.

Many cancer patients and their healthcare providers do not face up to approaching death until too late, and instead insist on increasingly aggressive medical care. Indeed several participants spoke of situations where radiation or chemotherapy was cancelled on the very morning it was to take place because the patient was expected to die within one or two days. Participants blamed this inability to face death as much on the patients themselves as on the physicians continuing the treatments. In our situational observations, supportive care physicians regretted that it was difficult to communicate with patients while they were still clinging to hope for a cure, under the influence of some oncologists.

(3) Meeting the costs of illness

The third is associated with trying to solve the financial problems associated with the patient's illness, such as loss of income, travels costs, or having to pay for childcare or nursing care.

Sometimes, it consists in finding extra-money for out-of-pocket payment from patient, but it is seldom in France, where cancer care is financed by the health insurance system which also routinely provides emergency financial. . Medical staff help to find solutions when problems occurs.

(4) Coordinating healthcare providers

The fourth section has to do with medical coordination of healthcare providers and their efforts to navigate through the complexity of the healthcare system, especially the bureaucratic challenge of receiving payment for the services they provide.

As a fragmented healthcare system, and a more fragmented social one is difficult to manage for patient, coordination is a necessity at several levels: medical, logistic, material. Having a place somewhere to discharge the patient is sometimes a challenge for hospitals.

(5) Respecting constraints

The fifth section relates to dealing with the constraints and obligations of the medical activities from a technical and a legal point of view. For example, a patient wants to return home but the healthcare professional has doubts about whether their technical ability to manage the next acute episode; or requests for euthanasia that clash with the law.

Sections *(1), (2) and (3)* are services functions, performed at the interface between patients and healthcare providers and therefore visible to the patient. Sections (4) and (5) are respectively technical and constraint functions in the sense of functional analysis, that take place outside the consultation room and are invisible to the patients.

Cohort study

The cohort study was conducted on 109 cases among 144 patients of the units considered (35 patients were excluded as they did not have cancer) (Table 2).

Table 2

Inclusion in the cohort study

Institution	**Services (cancer patient /total)**	**Patients**	**Selected patients**	**%**
Cancer hospital	Supportive care service and « week » beds (31/31)	31	11	35,5%
Hospital at Home	Cancer patients (62/96)	62	11	17,7%
Local hospital	Cancer patient of palliative service (16/17)	16	8	50%
Total		109	30	27,5%

In situations where medical needs were dominant, it was too difficult to distinguish medical from non-medical care. We therefore focused on patients whose need for non-medical supportive care was foremost and medical needs were secondary. This is not to say that for the patients whose medical needs were foremost their healthcare providers did not provide them with non-medical supportive care.

Of the 109 patients, 79 would have been adequately served by a hospital structure devoted to the primary function of procuring physical relief solely in the medical sense. 30 patients required firstly non-medical supportive care (table

3). Youngest was 45, oldest was 91. 22 were more than 60 and 16 more than 65. Half lived in rural areas, and the other half in urban or suburban. 16 were men and 14 women. They were having an unfavorable prognosis, with 11 different types of cancer, metastatic for at least 16.

Table 3

Functions mobilised in the cohort study

Place in the cohorte	**Hospital at Home**											**Hospital**										**Local hospital**							
Prolong life span																			X										
Reduce physical pain	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X		X				X	X	X		X			X
Preserve or recall physical functions	X	X	X	X	X	X	X		X	X	X		X	X	X	X		X			X		X	X	X		X	X		X
Slow down physical deterioration	X	X	X	X	X	X	X	X	X	X	X		X	X		X		X			X	X	X	X	X	X	X		X	X
Assure daily living requirements : housing, hygiene, meals			S		S	S		S				X	X	X	X	X	X	X	X	P	X	X	X	S	P	P	S	P	X	X
Reassure ill person and families (safety, availability, continuity)												X	S																	
Reassure about possibility of appeal if anything wrong	S																													
Protect family relationships																		X											
Protect help natural caregivers face consequences of illness				P		S		P			S		P			S	S						P		S				P	P
protect family from being overwhelmed by illness (in particular children)															P															
Protect stable family relationships								S																						
Protect ill person's autonomy		S			P																									
Help ill person set life goals			P				S		X													P			S					
Accompany ill person and families when illness is announced																														
Accompany ill person and families when worsening of illness is announced	S											P		X		P														
Accompany ill person and families when they are physically deteriorating						S										X													S	
Accompany ill person and families when they are facing the threat of approaching death																	P													
Meeting costs of care		P			S																									
Meeting costs of accompanying ill person through additional benefits																									S					
Meeting costs of accompanying ill person through other assistance to the ill person and their family	X					X		S		X																				
Coordinate medical skills (emergency procedures, pain management…)	P	X		S			X	X	X					S																
Coordinate caregivers				S	S																									
Coordinate logistics and social skills			S				X				P							P												
Adapt to diversity of ill person (languages, specific needs…)								X											S											
Face with objectives and constraints of workers and institutions						P	P	S	P	P		S	X	P			S	S			P			P			P			
Respect legal and technical obligation																			P											

P : Primary function S : secondary function X Done, but could have been done elsewhere

The reasons of their hospitalization were:

1) patient or family caregiver needed relief during a particularly distressing period (n=13)

2) barriers or dysfunctions of the organization made discharge impossible, such as no beds in palliative care available or no assured emergency services available locally (n=12)

3) patient was unable to perform basic activities for daily living and had no family caregivers available to help them (n=4);

4) patient could not meet the costs of illness, i.e. expansive treatment that could not be reimbursed if they are provided outside hospital (n=1);

5) patient refused to return home and hospital could not legally discharge them (n=1).

These patients also have medical assistance, with physical relief function as prolonging life or reducing pain.

DISCUSSION

It this paper, we analysed to what extent non-medical supportive care services for patients with advanced cancer are requested, provided, and masked as medical services.

We showed that a variety of non-medical supportive care are provided by healthcare professionals under the guise of medical care, and seen as a secondary resource by hospital administrations, where cure is the main goal and justifies the use of financial resources. Healthcare providers give non-medical supportive care financial credibility by using medical reasons to justify the use of resources, knowing that cancer patients always need medical and nursing care.

Distressed patients use more medical services than less distressed ones [21]. This is creating overuse of medical institutions or services. Some patients, psychologically fragile, socially isolated, or just temporarily exhausted, need specific attention, the nature of which will vary at different points in the course of the disease. They might also need help to overcome financial, logistical or bureaucratic barriers, or moral support to cope with disease and death. In addition to patients, close relatives or family caregivers need attention and help also, as it emerged in the literature [22,23]. Professionals worry about their capacity in the future to continue to provide non-medical supportive care in the context of healthcare budget cuts.

We do not consider that there is a conflict between curative and palliative medical functions and all the other forms of non-medical supportive care that provide the relief necessary to maintain some quality of life. Non-medical supportive care should rather be integrated into medical care, complementing or even replacing it. Requests for physical relief that often conceal a need for mental relief are a way for patients to gain the healthcare provider's attention or find an affordable way to gain temporary respite from the emotional burden of accompanying a dying relative. But the development of technical services designed for aggressive treatments and pricing based on the technical sophistication of care have strengthened the position of medical care at the expense of non-medical ones.

Patients may mask their request for non-medical supportive care because they dare not ask for it openly or do not know where else to find it. A caring response to a masked request for non-medical supportive care through the medical structure not only means that the costs are covered. Patients can also benefit from psychosocial intervention during the early phase of palliative care and discover that their symptoms can be relieved by something other than a drug prescription. Several studies showed evidence of patients benefitting from early palliative care that includes psychosocial support [24,25], less aggressive treatment, and better survival and quality of life [26–29]. Discussions

about end-of-life care can make it easier for patients to let go of increasingly aggressive treatments [30–32]. However, such discussions often occur too late in the process [33].

This study also shows that oncologists, like patients and their family caregivers, have difficulty facing approaching death, and this affects their own decisions about how and where patient management takes place. Direct moral support or anticipation of problems in local healthcare services can enable the patient's quality of life to be maintained for as long as possible. A coordinated healthcare team that can foresee and provide non-medical supportive care so that hospitalisation can be avoided is providing services that are at least as important as the quality of medical care. Doing that involves several disciplines at once.

Limitations

Our qualitative study is per definition not statistically representative. The functional analysis was performed on all the interview data, but the cohort study focused on how another group of patients makes use of the functions identified, we cannot generalize from our results. In the cohort study, inclusion of people who were inpatients for non-medical reasons meant that the study did not account for requests and responses for non-medical supportive care that took place within the context of medical consultations.

CONCLUSION

Medical care is not sufficient for the support of advanced cancer patients. Our results showed that they are often hospitalized for medical reasons that mask a more pressing need for non-medical attention. Even though equivalence of care (hospital/home care) is guaranteed, healthcare providers often provide these non-medical services within the hospital's medical patient management and medical funding structures because adequate non-medical care is not provided or funded anywhere else.

We showed the importance of non-medical supportive care, and the need for it to be fully appropriated and integrated rather than considered an accessory. This requires all healthcare professionals involved to increase their investment in the relationship with the patient and his or her family caregivers, giving them an opportunity to verbalize their requests and not insisting they stick to medical matters. In the context of budget cuts, a focus on purely medical functions will be counterproductive both financially and in terms of quality of care, in that this will force patients to continue to translate their needs for moral support into medical requests and force physicians to continue to respond in structural contexts that are inappropriate.

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Footnotes

Contributors VB designed data collection tools, monitored data collection for the whole trial, cleaned and analysed the data, and drafted and revised the paper. She is guarantor. VB, NM and JM implemented the trial, analysed the data, and drafted and revised the paper. NM monitored data collection for the whole trial, and revised the draft paper. VB, NM and JM revised the draft paper. The guarantor accepts full responsibility for the conduct of the study, had access to the data, and controlled the decision to publish.

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Competing interest None

Ethics approval Ethics committee of the Comprehensive Cancer Centre Leon Bérard

Data sharing statement All data relating to this study are available at https://hal.archives-ouvertes.fr/hal-01133371/document